Designing Communication Technologies for Socially Isolated Older People: Fieldwork Reflections

Abstract

In this paper we reflect on the challenges we encountered when conducting research with socially isolated older people. We examine how our participants’ vulnerability affected our conceptualization of social isolation and altered our approach to investigating it. The vulnerability of our participants and complexities of social isolation created fieldwork challenges, raising methodological and ethical issues for us to consider in our future work. Our field study informs the ongoing development and evaluation of a socio-technical system that aims to help ameliorate older people’s experience of social isolation.

Author Keywords
Social isolation; older people; qualitative research

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Old age is often associated with vulnerability [12]. Consequently there is a need for caution and sensitivity when conducting research with older people [11]. Within the HCI literature there has been great interest
in the design of technologies to help alleviate some of the vulnerabilities faced by older people [e.g., 2, 6]. Researchers have noted, however, that designing technologies for, and with, older people, requires specific strategies to ensure that older participants feel comfortable contributing to the research and design process [e.g., 8, 14]. Particular care is required when designing technologies for older people who have specific vulnerabilities, such as loneliness or isolation. The act of conducting research in these sensitive areas runs the risk of highlighting participants’ vulnerability, and potentially worsening the situation [11]. This can be confronting for both participants and researchers.

In this paper we reflect on the methodological challenges encountered during fieldwork investigating the design of a socio-technical system for older people who are socially isolated. The fieldwork aimed to gain a better understanding of older people’s experiences of social isolation in order to inform the ongoing design and evaluation of a tablet application. We experienced a number of challenges, which served to highlight the vulnerability of our participants and the risks associated with conducting this type of research. We reflect on these challenges below, following a brief discussion of social isolation and vulnerability in old age.

**Vulnerability and Social Isolation**

It is overly simplistic to say that all older people are vulnerable. Differences in personal circumstances and life histories mean that individual experiences of ageing can vary greatly [12]. Nevertheless, there are many aspects of ageing (such as poverty and poor health) that can make older people vulnerable to experiencing difficulties such as social isolation.

Social isolation is a “state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and [is] deficient in fulfilling and quality relationships” [10]. While not limited to old age, social isolation can be exacerbated by ageing. As people age they may experience reduced mobility, changes in life roles, bereavement, and decreasing social networks. These experiences can threaten a person’s feeling of belonging and limit opportunities for social interactions, making older people vulnerable to isolation. Social isolation, in turn, can make older people more vulnerable to numerous health problems and increase their vulnerability at times of crisis [12].

Today, as more people live longer and choose to age-in-place, the issue of social isolation among older people has become a prominent research concern [13]. Within the field of HCI, there is a growing interest in the design of social technologies for older people to help address this issue [4, 5]. Our work contributes to this field. We are developing and trialing a communication tool that aims to help isolated older people build new social connections. We are working with participants who are typically over 80 years old, have very little contact with other people and have limited or no experience with modern ICT.

In order to design technologies that effectively meet the needs of socially isolated older people, we need to understand the concept of social isolation and how older people experience it. Some valuable understanding can be derived from the knowledge and definitions offered in the literature, particularly within the fields of sociology and gerontology, in which there have been many attempts to conceptualize and
measure older people’s experience of social isolation [e.g., 10, 13]. However, definitions vary widely. In particular there are disagreements over the distinction between isolation and loneliness and the emphasis that different authors place on objective notions of isolation (i.e., number of social attachments) and subjective features (e.g., feeling of belongingness) [10]. What is apparent from this literature, is that social isolation is a complex phenomenon that involves “multiple realities” and requires a multifaceted research approach [13].

Fieldwork Reflections

We are currently undertaking a field study with a small group of older people, using a combination of semi-structured interviews and established questionnaires to measure and understand our participants’ experiences of social isolation. The nine participants in our field study are aged 67 to 93 (average age 83). They live at home and are clients of a local aged care provider. A care manager, employed by the provider, visits every few weeks to ensure the clients are well and to organize further support as needed. Clients were selected to participate because they were identified by their care managers as being – or at risk of being – socially isolated. Most participants are in their 80s and 90s. The two younger participants (both around 70) have significant health or mobility problems that make them eligible for support from the care provider.

During the three-month study, participants use our Enmesh iPad application to create photographs and messages to share with each other and with their care managers. The details of Enmesh are described in studies of an earlier prototype version [14, 15]. In the current study, we are field-testing an extended version of Enmesh to inform its ongoing development, and to gain a better understanding of our participants’ experiences of isolation. Here we reflect on the methodological issues that emerged when addressing the latter aim.

Measuring social isolation

At the start of the field study, a researcher visited participants to introduce them to the research and the technology, and to conduct an initial interview. During these interviews, we measured social isolation using two established instruments – the Friendship Scale [7] and the Lubben Social Network Scale [9]. These instruments were chosen because they were designed to be used by older people, and they each measure slightly different aspects of social isolation. The Friendship Scale focuses on the subjective experience and the Lubben Scale addresses the quantitative aspects of social isolation (i.e., number of contacts). Both scales were designed as self-administered questionnaires, with six items each. However, we chose to administer them as structured interview questions, to make it easier for participants to complete the measurements and to enable us to incorporate the measures seamlessly into the research process, which primarily uses qualitative methods.

In some ways this worked well. The questionnaire items were useful prompts, leading some participants to provide detailed descriptions of their relationships and social interactions. Some participants seemed to enjoy talking about their social circumstances and were matter-of-fact when reflecting on the paucity of relationships in their lives. Others, however, became noticeably distressed when talking about their social contacts. Sarah (aged around 70) had a particularly complex response to these questions. Sarah is a widow...
whose main family contact is a relative who lives out of town and visits occasionally. During the interview, Sarah began to cry while simultaneously explaining that she did not feel lonely because she used technology to keep busy by researching information of interest to her. The apparent conflict between her emotional state and the defiance she expressed in the face of isolation could reflect a reluctance to acknowledge being lonely. This is a common challenge when researching older people’s experience of isolation: older people may be reluctant to acknowledge their feelings of isolation or loneliness because doing so can compromise their status as independent people [11].

Managing emotional responses
We found that questioning participants about their experience of social isolation was sometimes quite confronting. One participant, Harry (over 90 years old), became very emotional when asked if he had felt isolated from others in the past four weeks (an item on the Friendship Scale). He responded "almost always" and explained this was due to hearing loss, which had become progressively worse in the past few years. He said he felt disconnected from people because he could not hear them, particularly in social settings, which he tries to avoid. He was clearly upset by this question and at this point became reluctant to engage with the research, answering the remaining questions with one-word responses. Harry then felt guilty about the brevity of our interview, expressing regret that he had not (in his opinion) been of use to us. Although we assured him that the information he provided was useful and that he was under no obligation to answer questions that he didn’t want to answer, it was clear that he felt as though he had “failed”. It appears that this feeling of inadequacy may have highlighted his vulnerability. This experience led us to modify our interview protocol. During the remaining interviews we did not administer the Friendship Scale in person; instead we left a paper version of the questionnaire with participants and asked them to complete it in their own time. We hoped that this would make the questionnaire less confronting. This did not appear to be the case, however: another participant (around 90 years old) withdrew from the study within the first week after attempting to answer the questions in the self-administered Friendship Scale.

The researcher’s role
Because our participants had limited opportunities to communicate with other people, care was required in managing the researcher-participant relationship. It became apparent during the initial meeting with Sarah that she craved conversation. She greeted the researcher by immediately asking questions about the researcher’s educational background, responding with details of her own education, which included a university degree. It was clear from this exchange that Sarah was looking for opportunities to converse with like-minded people. Later, she acknowledged that she could sometimes go days without talking to anybody, except the people she saw briefly at the shops. For someone in Sarah’s situation, opportunities for in-depth conversations are likely to be limited. The casual acquaintances she might encounter at the shops or in her local neighborhood would likely see her as a frail old woman, rather than a highly educated person.

This experience highlighted the difficulty of maintaining appropriate roles when meeting people like Sarah. It is, of course, important to build rapport with participants when undertaking qualitative fieldwork, and exchanging information is part of this process [1]. Participants who
are isolated and yearning for human contact, however, may value this exchange highly, raising challenges for the ongoing research relationship. Similar concerns were noted by Russell [11] who reported that in her study of isolated older people one man said the visit from the researcher was the longest time he had spent with anyone in the past eight years.

Challenging assumptions about social isolation
Our initial reflections on the interview data reveal the complexity of social isolation. Participants’ subjective experiences of social isolation varied greatly and seemed to be closely associated with their life histories and expectations, along with the objective realities of their current situation. This led us to confront our assumptions about isolation. When recruiting participants we prioritized older people who live alone, believing this was a strong indication of isolation. The care organization, however, nominated several clients who live with, or close to, family members. During the interviews it became clear that social isolation is a complex phenomenon that cannot be measured simply by the number of people an individual has contact with.

One participant, Louisa (over 90 years old), who lives alone, has never married or had children and has limited opportunities to see friends or family, seemed quite happy with her situation. She seemed comfortable with her own company and was very competent at filling in her time. Like Sarah, she used the Internet to look up topics of interest, keeping busy through lifelong learning. Louisa’s experience can be contrasted with Jane (about 90 years old) who lives with her husband and has a large family. Although Jane appeared to have a lot of contact with family, she did not feel as though she had sufficient social support. At the time of the field study, Jane’s family was experiencing difficulties, creating distress for Jane and her husband. Jane became emotional when asked about the support she receives from family members, which was now at risk because of the family troubles. Although her score on the social isolation measures was quite high, indicating low levels of isolation, Jane clearly felt that her current situation made her vulnerable to increased isolation.

Conclusion
Our fieldwork experiences highlight a number of challenges faced when examining older people’s experiences of social isolation. In order to gain an in-depth understanding of the needs of vulnerable people, researchers are required to come face-to-face with participants’ vulnerability. We found that the vulnerability of our participants – particularly with respect to their limited opportunities for social interactions – meant they sometimes desired further contact with researchers. However, this needed to be carefully negotiated in the context of the ongoing researcher-participant relationship. Maintaining appropriate roles is a common challenge for researchers conducting ethnographic or qualitative fieldwork [1], particularly when the research focuses on a sensitive topic [3].

Additionally, measuring social isolation presented unique challenges. Although we used established instruments, we found that items from these measures sometimes elicited complex responses. In some cases, the questions served to highlight participants’ vulnerability. On at least two occasions the sensitive nature of the questions limited participants’ contributions to the research. In these cases we may have inadvertently increased participants’ vulnerability.
by making them feel inadequate when they were unable to fully contribute to the research. Although we reassured participants that they did not have to answer any questions they found uncomfortable, it is possible that these reassurances did not fully mitigate participants’ feelings of failure.

Our research also challenged our assumptions about social isolation. We found that social isolation cannot be easily defined by life circumstances or objective measures. Research into social isolation, then, must recognize the multiple ways in which isolation can be experienced by individuals. This raises the question of how to best investigate and interpret different people’s lived realities of social isolation, and highlights the challenges involved in effectively designing technologies to meet the diverse needs of socially isolated older people. In this paper we have described the challenges we encountered in our attempts to understand older people’s experience of social isolation. Our reflections on our fieldwork experiences highlight ethical and methodological issues that require further consideration to inform our ongoing work on this topic.

References